



The Benefit of Consumer Involvement in Homeless Management Information Systems

An Edited Transcript of the PATH National Teleconference
Sponsored by the Substance Abuse and Mental Health Services Administration (SAMHSA)

July 27, 2005

Presenters:

Julia Tripp, Advocates for Human Potential and the Center for Social Policy,
University of Massachusetts, Boston

Kathleen Freeman, HMIS System Administrator and Project Manager,
State of Maine

Linda Corey, Executive Director of Vermont Psychiatric Survivors

Moderator:

Ann Denton

Advocates for Human Potential, Inc., Delmar, New York

This telephone/Internet presentation was supported by a technical assistance contract with the Substance Abuse and Mental Health Services Administration (SAMHSA). However, the content of this teleconference does not necessarily reflect the views of SAMHSA or the U.S. Department of Health and Human Services. For further information about this teleconference, please contact Phyllis Liu, Advocates for Human Potential, Inc. (518) 475-9146.

Table of Contents

Welcome and Introduction	3
Homeless Management Information Systems (HMIS)	3
Today’s Speakers	3
One Consumer’s Involvement with HMIS.....	4
Consumer Privacy and HMIS.....	5
Consumers and HMIS in Vermont.....	7
The Benefits of Consumer Involvement.....	8
How to Engage Consumers.....	9
HMIS in Maine	10
A Review of Major Lessons	12
Discussion	13
Teaching Consumers about HMIS	14
Obtaining Informed Consent.....	14
Ending the “Us-and-Them” Divide.....	15
Paying for Consumer Involvement	16
Final Thoughts and Conclusion.....	17

Welcome and Introduction

Ann Denton

Thank you. Hello, everyone, and welcome to today's PATH teleconference. Our topic is the Benefit of Consumer Involvement in Homeless Management Information Systems. My name is Ann Denton and I'm from Advocates for Human Potential in Albany, New York. With our colleagues at Policy Research Associates, we provide technical assistance for the PATH program. I'll be the moderator for today's presentation, and we're delighted to have with us Julia Tripp from AHP, Kat Freeman from the State of Maine, and Linda Corey from Vermont Psychiatric Survivors.

We're sure that this will be a most informative and helpful call to those of you who are looking to involve consumers in your local HMIS planning and implementation.

Questions will be taken at the end of the presentation.

Homeless Management Information Systems (HMIS)

I've been asked to give you a really quick overview about the Homeless Management Information Systems (HMIS). This is information that you all have or you would not be on this call, but I wanted to remind you that the primary purpose of the HMIS is to gather data on homelessness at local and national levels that describe the scope of the problem and the effectiveness of efforts to end homelessness. The HMIS system provides opportunities to improve services for people who are homeless and it also helps to strengthen community planning and resource allocation.

When the HMIS is done right, it provides important benefits at the consumer program and system levels. We'll talk today about privacy and security as part of consumer involvement in HMIS. Why do we care about privacy and security? Because clients share personal information during the HMIS process and information is recorded in the HMIS. Although the

intent of the HMIS is to provide benefits to clients, there's always a fear that information is accessible to people who could use it inappropriately. For these reasons, an HMIS always has to be secured with limitations as to how the information can be accessed, shared, modified, or used, and our presenters are going to discuss that a bit more. One of the very best ways to ensure that a system protects consumers and meets their needs is to involve them in planning, implementation, and operation processes and that's why we're all here today.

Today's Speakers

I would like to introduce our featured speakers. Our first presenter is Julia Tripp. Julia Tripp works part-time as a constituent coordinator with the John W. McCormack Graduate School of Policy Studies at the Center for Social Policy UMass Boston where she has been a consultant since 1998. She is also a part-time program associate with Advocates for Human Potential for PATH, and we're glad to have her. Julia brings her understanding of engaging chronically homeless and other challenged populations to both projects. As a consultant with HUD's national HMIS technical assistance project, Julia developed a philosophy and curriculum on consumer involvement in HMIS. Based on her own experience of homelessness and addiction, she has trained in over 40 communities across the country on this topic.

Our second presenter is Linda Corey. Linda is the executive director of Vermont Psychiatric Survivors. Vermont Psychiatric Survivors is a 501(c)(3) organization, running mostly on grants and donations. In the homeless sector, this organization, as a consumer organization, does the day-to-day operations of a homeless shelter and participates in statewide coalitions. Recovery is the primary belief, and Linda is effective in building consumer leadership and empowerment.

Our third presenter is Kathleen Freeman. Kat is the HMIS system administration and project manager for the State of Maine, dedicated HMIS. Her work experience is in data collection, system design, implementation, system administration, and program

analysis. She works for Maine State Housing Authority, who is the lead agency for Maine's HMIS. A former victim of domestic violence, she is co-chair of the technical committee of the New England Regional HMIS, as well as a board member of that organization. She also serves on the Nominating and Knowledge Management Committee of the National Human Services Data Consortium.

Welcome to you all. I'd now like to turn the call over to Julia.

Julia Tripp

Thank you. Good morning, everyone, and Linda, Kat, listeners. I'm glad to have this opportunity to speak with you today. My presentation will share how and why I became involved in implementation of the Homeless Management Information System, which hereafter we will call HMIS. I will explain how my work on consumer involvement came to be part of HUD's expectations for HMIS implementation and I will highlight some benefits of consumer involvement for both providers and consumers. I will also suggest how consumers can become more involved in national data collection efforts and how this can benefit everyone.

First let me tell you something about my background. I work part-time as a program associate with Advocates for Human Potential, Inc., and I'm also a constituent coordinator with the Center for Social Policy at the University of Massachusetts Boston, which hereafter I'll just call CSP. Nine years ago, I ended 11 years of homelessness and addiction, during which time I moved from one abandoned house to another, fitting the definition of a chronically homeless person. I'm employed full-time today and I'm the author of *Bring America Home*, a song named after the slogan of the National Coalition for the Homeless.

The coalition is known for creating the bill that became the Bringing America Home Act of 2003 HR 2897. The song is an anthem about my journey from addiction to activism, my own personal transformation. We are rehearsing to perform a skit that came out of this work to present at HUD's

National HMIS Conference in St. Louis, Missouri, on September 12 – 14. All the actors I engage in this project are currently or previously homeless and/or have experienced poverty.

One Consumer's Involvement with HMIS

My life was transformed as a result of my involvement as a consumer representative, especially because of my work on HMIS. Now I'm going to take a moment to tell you about the history of my involvement and how it opened the doors for more consumers to participate in their community's implementation of HMIS.

In 1998, after contributing to a privacy protection workgroup, I was invited to join the HMIS steering committee organized by the Center. From there, I was invited to join the National Homeless Services Data Users Group, now the NHSDC. As the discussions became more technical, the appropriateness of consumer involvement was questioned and I took a stand to defend our inclusion. I believed then and still do that the value consumers contribute to HMIS planning is worth the effort to include them and help them understand the system. At first I was not sure of the benefits of HMIS. I came under fire for not coming down on that side of the issue. At the same time, as I continued my work with the Center, I joined the National Coalition for the Homeless, NCH, which later strongly opposed HMIS, mostly because of privacy concerns. There was much that was not known about the system at that time and I didn't understand technology well enough to know how protections like encryption worked. I didn't know whether data was shared or that I had any rights to consent or not. I was also unaware of legal protections like HIPAA, the Health Insurance Portability and Accountability Act of 1996. At first, I also did not realize that the system would capture information on providers as well as consumers. But I was steadfast in my belief that the best approach to HMIS implementation was to develop it with input from informed consumers. I followed the HIV/AIDS advocacy motto, which says, "Nothing about us without us."

Because I believed in the importance of consumer involvement and I believed we had something to contribute to HMIS, as well as other Center projects, I asked to initiate and manage a consumer advisory committee for the Center and they agreed. I brought in consumers who had experienced homelessness to join the committee, include people who represented families and the mental health, domestic violence, HIV/AIDS, disability, corrections, and recovery communities. We learned together about technology. We learned more slowly, at our own pace, but we did learn. Along the way, we became empowered to voice our concerns in this and other arenas.

In 1999, I had the privilege of participating in the early stages of the implementation process with Seattle's Safe Harbor project. I witnessed the development of a vision for the system and the development of workgroups and subcommittees to discuss issues like data quality and access to data and privacy concerns. For the first time, as the system was tested, I really understood what was meant by data elements, which are the questions that are being asked, and the system structure, which means the way computers in an agency are linked. Throughout the process, two or three consumers were involved in Seattle, but the larger part of the homeless community felt disenfranchised and organized against it. Because I saw it from both sides, I came to believe that the process a community goes through to implement a HMIS is a very important one with real benefits for consumers as well as providers.

To be able to involve consumers successfully, however, engagement in HMIS must happen on two fronts. One, consumers can contribute information related to the assistance and services that they need, which in turn provides needed information on service gaps and needs. Two, they can participate in decision making as representatives of other homeless consumers. Consumer involvement in HMIS is not just giving information to get services. I was fortunate to have an opportunity to help consumer involvement in HMIS become a reality nationwide.

In 2000, after the Center for Social Policy helped Seattle successfully implement a HMIS, the center won the first of two HUD contracts for the National

HMIS implementation. Again, I was invited to participate and was hired as a consultant to develop a philosophy and a national model for consumer involvement in HMIS. Based on my experiences of community participation, as well as the feedback of many other consumers, I then delivered and refined my work in over 30 trainings from the East to the West Coast, including Maine and New Hampshire, States that are on this call today to discuss how they've implemented consumer involvement in HMIS in their communities. I laid out the entire process according to my experience in engaging and training consumers. I laid out the methodology we used, the benefits and challenges we experienced and strategies for educating consumers. We were learning in Boston that informing consumers about privacy and security freed them to choose to participate. I'm honored to have been part of the Maine and New Hampshire process. Today HUD has embraced this model of consumer participation and all communities are being encouraged to use this as they implement HMIS.

Consumer Privacy and HMIS

While I now understand HMIS better and see its potential, the risks to consumers' privacy are real and, in some cases, life threatening. These risks must be acknowledged. Procedures for protecting consumers must be explained clearly to them if you hope to gain their cooperation. The population as a whole has reasons for concern about the release of personal information. For many individuals who have experienced homelessness, there are particular concerns about the consequences of a breach of privacy. For example, if a homeless person is arrested or has a jail record, disclosure of that fact may cause that person to be treated differently by other staff and clients. That individual could be denied badly needed services or shelter. This doubly victimizes them. What about the spouse who's escaping domestic violence? This person could be exposed by careless information handling and his or her safety placed at risk. A person living with HIV/AIDS can be unfairly discriminated against if this information is leaked. Because of the potential for stigmatization, the information that an individual is in recovery from drug or alcohol addiction should not be released

without that person's permission. What is especially egregious about all of these breaches is that they can lead to discrimination against individuals struggling to regain control of their lives. Leaked information could result in treatment that prohibits or prevents their progress.

Providers need to be aware that explaining to consumers how their information is collected and protected will not only help consumers to feel safe to participate, but will also empower them to take an active role to protect themselves while they are in the system and, later, when they exit the system. The risks are real and always an issue. But what many consumers may not know is that there are some very strict safeguards and consequences in place. As many of our listeners do know, information is protected by Federal, State and program policies, including informed consent and grievance procedures. HMIS also uses technical solutions, such as encryption, certificates, firewalls, and public key infrastructure (PKI) to deter or prevent piracy or hacking. A link to information on HIPAA requirements, which provide further protections, has been posted on the PATH Web site.

Consumers should also have the right to file a grievance if their privacy is violated. You will also find a sample grievance form on the PATH Web site that can be a starting point for your agency's work in this area. It is reassuring and important to consumers to know that program; State and Federal policies provide for consequences if their right to privacy is violated. Staff and advocates must understand these protections and consequences so they can explain these to consumers. The policies and procedures or grievance committee can form a program policy for violations. Consumers must be able to participate on these committees.

Now I'd like to take a moment to explore what we mean by consumer involvement and suggest some ways that this could happen in your community. By consumers, I am referring to people who have been homeless; who are moving from homelessness; or who are currently homeless; and whose perspectives are necessary for service providers to learn about what works and what doesn't work. They include families

and individuals with mental illness, health disorders, and substance abuse disorders; those who have co-occurring mental and substance abuse disorders; and survivors of domestic violence. They include people of all ages and many diverse experiences.

This mix of consumers can provide clues to the gaps in homeless services and can help providers succeed in serving them. By involvement, I mean consumers assisting in brainstorming, evaluating, and decision-making about the services they need and use, as well as in HMIS implementation. Communities can increase consumer participation by inviting consumers to attend community meetings, the continuum-of-care meetings, or by recommending or nominating them to serve on advisory boards, or by hiring them as agency staff. We can institute or encourage programs and organizations that are completely run by consumers. Agencies can involve consumers by training them on HMIS in user groups. These should be geared to the range of literacy levels in the homeless community. These trainings should cover several issues, such as how data helps determine gaps and needs and how these data impact public policy, how programs are funded, what questions will be asked of the consumer, how data are collected and privacy protected, whether information is being shared or not, and the choices and risks associated with data sharing and technology issues such as software and access to data, as well as data quality. A curriculum would resemble a typical staff user group, but can be more general in nature. It should include an overview and time to respond to consumer questions. It should also include or encourage deeper learning, if desired. At least, involvement should mean that consumers receive the knowledge they need in a timely and culturally sensitive manner.

For any concerted effort to engage, inform and/or educate consumers on HMIS, consider developing communication tools. These don't have to be complicated, but the objective needs to be clear. A communication tool can be as simple as a poster telling people what you are doing, how you are doing it, and why, or a visual aid or flowchart that shows this information in a picture. You can develop a simple flowchart that shows the steps in the

process: entering information, accessing services, running reports, and improving program and public policy. You can show them how information will be aggregated. I have seen simple drawings used as successfully with staff as with consumers. A great example is a recent training called “HMIS Privacy Protections for Consumers,” presented by CSP staff person Bill Sylvestry for a workshop we were holding recently for consumers. Bill used drawings to show the various ways information on computers would be protected. Now I’d like to turn it over to Linda Corey.

Consumers and HMIS in Vermont

Linda Corey

Hi. My name is Linda Corey, and I am from Vermont. I’m the executive director of the Statewide Consumer Agency, Vermont Psychiatric Survivors, known as VPS. We work closely with our State Division of Mental Health, particularly on housing, with a gentleman by the name of Brian Smith, whom many of you know. I sit on the committee that reviews PATH programs in Vermont. Another factor is that our organization oversees the day-to-day operations of a Safe Haven for people with mental health issues and who are homeless. This program is partially funded by a HUD grant.

Our work as advocates leads us to public presentations and giving support to those who have housing issues. Our organization is involved in the statewide continuum as well as many of the regional coalitions on housing. Vermont is involved with ServicePoint as a HMIS tool. (ServicePoint is a consumer information management system, or CIMS, that is Web-based and secure.) In 2004, we heard of Julia Tripp through Brian Smith. We were looking for consumer input on involving more consumers in the input of the needs of homeless people. This goes along with our involvement with recovery. We believe that, to have it happen, one must have the consumer as an equal partner in decision making.

VPS invited Julia to come and present to our statewide continuum. It was so successful that we had Julia back in 6 months to do a follow-up. We were asked about providing other trainings, and Joel

Slack came to us to present on “respect.” Joel Slack is a national presenter that belongs to RESPECT International. The idea is built on the word “respect.” To do that, we look at R as being responsive, E as encouraging, S as sensitive, P as perceptive, E as empowering, C as in caring and T as in thoughtful. After hearing this, we looked at these issues further. Some of the agencies now put a little piece on their wall to help remind them that, when working with consumers, these are things that need to happen. This led one program to develop a full board of consumers that runs a drop-in center, as well as a medical center, for people who are homeless. These consumers largely run the drop-in piece and the visits to their peers when they find a place to live. The statewide continuum appointed a consumer representative who volunteers in another program and has learned to use ServicePoint and does that in their program. This program is located within a drop-in center as well. Another consumer also was hired in a drop-in center that helps with the PATH programs and works with Brian Smith as well. This person does the ServicePoint documentation for their program and also helps two other programs.

Generally we send at least one consumer on the team to all regional and national conferences to learn and report back. This is also a way for the consumers to network. The bottom line is that, if a consumer is informed and a partner in developing programs and documentation tools, they feel more comfortable. When they are not aware of the process, it is unknown and often feared, so they resist.

These are the lessons we have learned in Vermont and we appreciate the time to share these. To discuss this further, you can reach me by my e-mail at ypsinc@sover.net. Thank you, and now I’ll turn this back to Julia.

The Benefits of Consumer Involvement

Julia Tripp

Thank you for that, Linda. Now I'd like to explore the benefits of consumer involvement, first for providers and next for consumers. One of the greatest benefits to the agency is the better use of services as a result of consumers being better informed. Providers can now clarify the services available. Consumers will know these, but will be more likely to use the services for which they are eligible, which promotes faster recovery, treatment, and access to services and housing. Also, as consumers come to understand the connection between funding and services, they are less likely to express resentment and suspicion of how resources are applied.

Informed consumers are more likely to invest in and commit to supporting agencies' efforts. This understanding of department functions will help build stronger advocates in the consumer pool. Informed consumers are also more likely to share accurate and complete information with the HMIS. Consumers' ideas and feedback are a practical benefit to the system. Consumer feedback improves the system's ease of use. Consumers can draw attention to system glitches that no one else may have noticed. It can also influence the design of security measures to reduce the likelihood of information-sharing abuse. The presence and integration of consumers into existing work groups will also help keep the work of these groups focused and more real, relevant, and rewarding.

Consumer presence sensitizes the service system to their right to be there. It associates abstract numbers with real people. Their presence can help system designers understand why a particular question may breach one's privacy. They can help with the periodic review of the privacy protections to see if they are still relevant or need strengthening. They can suggest the best time and ways to collect sensitive information. Because of their experience as persons who've experienced homelessness, consumers can suggest better ways of phrasing intake questions.

Providers gain because it makes their job easier during the intake process. They're dealing with well-informed consumers who know how the information will help create better services. Consumer involvement provides priceless input for improving the way data is collected and handled. Perhaps the overall biggest benefit of consumer involvement to the HMIS implementation is that it ensures that the system is designed to protect and meet the needs of consumers. These are only a few of the benefits, but they are some of the most important.

Now what are the distinct benefits to consumers themselves?

Socially, involvement connects people with a community. It provides support, learning, networking, and friendships among peers, providers, and policy and decision makers. Professionally, involvement changes your status in the world. You gain new skills and confidence. You network and meet people. They listen to you and invite you to present your point of view. Friendships previously impossible now develop. Job opportunities seemingly out of reach may now be within your grasp. And an unsavory reputation is transformed into a source of professional references and recommendations. As a result of this network, you now have relationships with people as well as those you've known from the community of persons who've experienced homelessness.

A consumer gains experience with good business practices, such as how group meetings are effectively run, how information is shared, and how to gain allies for a cause or an issue. A consumer may decide to get a GED or return to college, and they begin to see themselves as capable of taking advantage of job opportunities. Involvement demystifies the information-collection process, and people can see themselves as capable of working in the field and perhaps mentoring others. Involvement transforms more than the individual; it transforms the way people are perceived and services delivered. The best way to see these possibilities may be on an individual level.

My own experience illustrates the transformative power of consumer involvement. Too often this benefit is seen either as a secondary goal or not

understood at all by an agency. The benefits to consumers are not only at the system level, but on a personal, social and professional level as well. Involvement boosts the esteem of isolated and unemployed persons who face discrimination and stigma on a daily basis. Personally, my involvement acknowledged my value and improved my outlook. It provided hope, which strengthened me. Participating in the process offered opportunities for personal and professional progress. I also learned very important communication skills and decision-making processes, and this benefit to a family is enormous.

As participants learn about the importance of ground rules, for example, they can transfer that learning to their own relationships. So involvement provides a tapestry of benefits. It clearly empowered me and opened up many opportunities. For example, I participated on many boards and councils, became a public speaker, took advantage of professional development and leadership training, and I was hired to consult. My creativity was unleashed and, through my work, I can mentor others. Even though I experienced both failures and successes, I also learned invaluable lessons. Also, this exposure has so raised my awareness that today I vigilantly protect my personal information against identity theft and fraud. However, for me, the learning has often come very slowly, but the rewards have been great. I find that you take in new information and you begin to use it when the situation arises. I firmly believe that what worked for me can work in different ways for other consumers. You get out of it what you need at the place where you are at. I took on a leadership role. I've seen others gain a sense of empowerment as they put their voices forward. Many people have benefited each in his or her own way.

How to Engage Consumers

So where do you go from here and how do you start? Well, to help you decide your organization's next steps and invite your creativity, I'd like to close with some remarks on next steps. If you're doing any kind of consumer involvement, leadership training, capacity-building, or involvement, you're already heading in the right direction. These efforts can be

a natural springboard to HMIS involvement, and Vermont and Maine are here as excellent examples of that. But more needs to be done to bring the average consumer into the process. There are some key principles one should keep in mind.

First, engaging difficult-to-reach populations depends on intense, organized, effective outreach. Research has shown that consumer participation can improve psychological conditions, diminish substance abuse, and contribute to housing stability. I was impressed by a book called "Consumers as Providers in Psychiatric Rehabilitation," edited by Mowbray, Moxley, Jasper, & Howell, which demonstrates and discusses this principle. Consumer involvement is a vital link in the movement out of homelessness into employment.

Second, consumers should benefit from participation in the same kinds of user trainings that are given to providers and staff and they should be offered at appropriate literacy levels.

Third, realize that consumers' time is valuable just like everyone else's. We need to invest in providing opportunities for all consumers to receive basic information on HMIS implementation and be able to participate in the local continuum of care planning process. Do provide food and stipends or honorariums to respect their contributions and their time. If everyone else is paid to be there, and if you accept that a consumer has a great deal to offer the entire system, then it follows that this support is appropriate and needed.

Fourth, gaining support from staff is also critical. They may not agree initially with a shift towards education on HMIS as opposed to, say, vocational training. There may also be challenges from consumers who do not trust the system. So be prepared to do the preliminary work to ensure that all are on the same page.

Fifth, if you are beginning to involve consumers or have been involving consumers in your HMIS implementation, I recommend early evaluation to measure impact right from the start. Consider evaluating the impact on the individual and on the implementation process as well. This additional

information will provide valuable evidence demonstrating your program's effectiveness. It is also important that consumers you involve should not be tokens, because this could have a negative impact on the person and the process, which is exactly the opposite of what we want to achieve. Consumers need to debrief with peers as well as with technical staff. This process will not turn every consumer into an advocate or a person capable of being a case manager, staff person or consumer representative sitting on a workgroup or a committee, but it will attract a number of people who want to be engaged in meaningful activities that have the rewards of knowledge, influence, and income.

Your initial efforts may not draw huge participation in decision making, but participation reaps huge rewards and will benefit your implementation. I'd also like to mention that I've been sending out a questionnaire to get feedback on consumer involvement activities in HMIS, and I'd like to know about your experiences. If you're interested in contributing information to this effort, please e-mail me at jtripp@ahpnet.com, and I will send out a questionnaire for your feedback.

So what about systems that have already implemented a HMIS, but didn't involve consumers? Well, many communities already have done that and that's unfortunate, since those decisions cover key issues as information access, data sharing, data collection, unique identifiers, and the use of Social Security numbers. Our moderator, Ann Denton, says that the people impacted by the problem should always be included in the solution, and I agree. But if this has not been the case, it is not too late. Many policies and procedural decisions have to be revisited periodically. Consumers can be part of that process. And understand, too, that a consumer arriving late in the game will have to catch up on a lot of the technical, procedural, and legal issues and should not be expected to be up-to-speed immediately. But the personal benefits are realized for consumers no matter where they enter in the process. Now I'd like to turn it over to Kat.

HMIS in Maine

Kathleen Freeman

Good afternoon. Thank you, Julia. First I'd like to tell everyone about Maine's HMIS implementation. We are a dedicated, collaborative, statewide HMIS involving three continuums of care and multiple State agencies. It is unique to the nation in its design and offers various participation strategies. We do not rely on a product like ServicePoint for all of our data collection needs, and we can accept data from any external source. By using client-identifiable information for duplication and linking purposes only, we can link people to services received from health and human services, corrections, education, and Veteran's Administration data systems. The client-identifiable data is then stripped out and the remaining data is dumped into a reporting database for aggregate reporting and analysis. This unique design will provide, over time, a holistic view of homelessness in our State and will greatly enhance our services, systems, and process analysis. We have been live since March, 2004, and currently have 69 percent agency participation.

Every implementation has its weaknesses. Thanks to an assessment visit from QED (a minority non-profit that is the contractor for HMIS implementation) in August of 2004, we were lucky enough to be able to quickly identify our weakness, which was low consumer involvement. Additionally, the consumer meeting held by QED was a profoundly educating process for the HMIS project staff. We immediately embraced consumer involvement and saw the benefits to both consumer and the project by having this kind of involvement. We also realized the need for a system that benefited the clients directly and responded to funding stream needs. That realization has drastically changed the way decisions are made regarding HMIS.

After the consumer meeting, I and Yvonne Nichols, who is one of our homeless advocates here at Maine State Housing, began this wildly creative brainstorming process about the who, what, when, where, and how of getting consumers involved. Well, we still had another very important lesson to learn. We had left out the advocate. Within 24 hours,

we were fielding irate phone calls from the only organized consumer advocacy group in Maine. Now while QED had asked for a very specific consumer group for that meeting, which unfortunately did not include an organized advocacy group, it became very clear that this group had not only not been involved from the beginning, but that they felt that they should have been. They now meant to have an impact on the HMIS implementation and not in a positive way. Their mistrust of the HMIS system and project staff spilled over to consumers directly, who refused to sign releases of information to have their data loaded into HMIS.

Clearly we had to do something, so we started an aggressive campaign to bring the advocates to the table. Yvonne Nichols worked with the advocates. She took it on the chin. She attended many meetings with the advocates and validated their feelings. After all, they were right on the spot. They deserved to be angry, because they hadn't been included, and we freely acknowledged that we were wrong and indicated we wanted to change that. So Yvonne's work paved the way for a more technical discussion on data security, client confidentiality, and consumer education issues. The advocates started to ask technical questions that Yvonne could not answer, so we set up a meeting where I could showcase the system's security and answer some of their technical questions. At the same time, I had drafted a number of consumer education posters, and Yvonne was working on a brochure that explained HMIS for consumer consumption. After asking for feedback from a number of different entities, including the New England Regional HMIS (NER HMIS), Yvonne and I took these revised versions of these materials with us to the advocacy meeting for their input and feedback.

Now this process accomplished three things. First, our efforts to find ways to educate consumers brought empowerment to the advocacy group. Because we clearly accepted our responsibility for our involvement oversight and because we were aggressively working on correcting that due to their intervention, the advocacy group entered into a meaningful discussion with us about what information was appropriate and useful, what

information consumers would be most interested in, and how we should deliver it, and we listened.

Second and perhaps most unexpected was that we brought the idea of consumer education involvement to a whole new level, both statewide and regionally. Talking about consumer involvement became action for getting consumer involvement. Perhaps the most surprising thing for me was the hesitation by some provider agencies to accept our proposed educational program, because they felt that consumers would feel empowered and that they deserved to impact services and delivery. So we discovered that we were going to have to provide some education on multiple levels, not just to consumers. But I'm not going to talk about that today.

Third and perhaps the most profound was the reaction of the advocates to the showcasing of the system security and then talking with me. As we sat in a room and signed on to our central database, they could see the encryption in place and that no client-identifiable information was viewable. They began to ask questions about system security and client confidentiality policies and, in the end, felt much safer contributing data to a central database. They even discussed concepts of sharing data between agencies and what that could mean for them. We talked about how they control their information and that its responsibility, as well as ours, is to make sure that agencies who participate in HMIS are adhering to security and confidentiality policies. We discussed the difficulty in explaining technical security terms and talked about how to deliver that information to consumers. We talked about how they had the right to police what happens to the information and how they can influence both the types of services provided as well as how they are provided.

This meeting served as a turning point for the relationship between the HMIS project and the advocates. I thank the Preble Street Advocates for their willingness to be patient in educating us. Within 24 hours of this meeting, the percentage of releases of information being signed by clients in the largest and the lowest barrier shelter in Maine jumped by 20 percent.

So where are we now? We have developed a survey process to assess if our education program is effective and meaningful. We are hoping that client education will naturally involve consumers in some of the more technical aspects of the system design. We've also completed two brochures; one entitled "HMIS System Security," and the other entitled "HMIS System Security and Client Confidentiality." We've also developed a series of posters. These documents provide general information that hopefully will lead to further discussion. These documents are available on the Maine HMIS Web site and the NER HMIS Web site. A link to the Maine HMIS Web site is on the PATH Web site. The HMIS project staff and the homeless advocates will train the advocacy group, then their general membership, and then we will visit all of the larger shelters around the State and train and educate consumers about their rights and HMIS and technical solutions.

A critical point to this entire education is our belief that consumers should be educated in general about their rights, not just because we have an HMIS. We believe that by educating the clients that we will naturally find those who want to be involved. We hope these materials that we have developed can be expanded and refined as time goes on.

So in ending, the Maine HMIS project staff suggests the following to you. Clients can and should be able to force agencies to share data to expedite the service delivery and ease the oppression of having to repeat their stories over and over and over again. Clients can and should affect what services are provided and they can make that assessment by understanding the link between funding and services and providing feedback. Clients can and should police whether their information is being protected, particularly at the agency level, and that confidentiality policies are being adhered to. Clients can and should be educated about how and when they can advocate for service, systems, and policy changes. If you involve clients you will have a better system because of it. Thank you for your time, and I'll turn this call back to Julia.

Julia Tripp

Thank you. That was great. Again, Kat, it was an honor to be part of your process and Linda's as well. So in closing, I'd just like to review the major points.

A Review of Major Lessons

First and foremost, and this is redundant, but is worth repeating: consumers are major stakeholders in the HMIS implementation process. They have the right to learn about the system and be involved in relevant decisions. They should be informed of its benefits and risks. They should also be engaged to develop more effective services. It will empower them and open doors that can help them change their lives. Secondly, consumers need to understand that better and more effective programs need data. Continued program funding depends on good data as well as on program effectiveness. The bottom line: communicate these things clearly to consumers.

The final point is one that I'm very passionate about, the fact that we all need to be prepared for civic responsibility in our lives and in our communities. I would like to see more homeless individuals or direct consumers empowered in this area of their lives. These opportunities for positions of authority and/or influence come through community involvement. This is an important vector and rung on a career ladder. According to another colleague, John Rio from AHP, we should be thinking about people graduating from chronic homelessness and help them find a place in the workforce. This is not just the right thing to do; it's the smart thing to do. If you want to strengthen your privacy protection, increase data quality, upgrade program outcome, improve relations with the people you serve and improve people's lives, consumers should be included in your agency's HMIS implementation process.

I hope that our presentations and my firsthand testimony will prove that consumer involvement does work and that it serves to promote systemic transformation and to end the social isolation that contributes to homelessness and poverty. Thank you. I'm now going to turn it back over to our moderator, Ann.

Discussion

Ann Denton

I want to start by thanking each and every one of you for what I consider to be an excellent presentation. We're now going to open up the question and answer period.

Q. The first question is for Julia and it is: You said consumer involvement in HMIS is not just giving information to get services. Why do you stress that?

Julia Tripp

Because I never wanted consumers to be co-opted into participation in the system. The gold standard of consumer involvement in HMIS would be to engage consumers throughout the entire process, not just as an afterthought. That's because it could become little more than a focus group, which has its merits, but doesn't deliver the biggest benefit to the consumer. That happens with full integration into the process. I will always push for deepening the benefit in this way.

Ann Denton

Q. Okay. Thank you, Julia. I have a question for Linda from e-mail: Can you specify the elements of consumer involvement that work?

Linda Corey

With the Safe Haven that we run, we actually have some people there working who actually used to live there. They have gone on to college, as Julia mentioned, and are moving forward in the leadership. Because the place is operated on the basis of recovery, the people's input has been very positive. Having people and consumers involved in the other areas, as I mentioned, actually putting the information in to the computer and learning how to do work—as I said, we use the ServicePoint piece—has been beneficial because the other consumers feel more comfortable sometimes if they know that they have some peers that are involved with it in helping to explain to them about what all this is and how it works.

Ann Denton

Q. Okay. This one, Kat, is for you: How has the concept of client involvement changed the development of your actual HMIS system?

Kathleen Freeman

I mentioned earlier that the process had changed our development and focus. The biggest change is that we've responded to HUD and its mandates. In almost all cases, data systems are created to benefit agencies and not clients. So agencies erroneously believe that by making their systems more efficient that efficiency will naturally flow over into faster and better service delivery, which is not always true. So we want to change that. We want to have a system that really is a benefit to the clients as well as agencies. As an example of that, if it's advantageous for a client that certain agencies share identifiable information with another agency, then the clients can have an impact on whether that sharing occurs and what controls are put on it.

I believe that once clients are more educated about funding streams and services, they're going to help change services and policies. They are the people we're trying to serve. So every time we discuss a new development idea, we ask ourselves four questions. The first is, "How will this development provide better services to the client?" Another is, "How will this development affect client data confidentiality?" and then, "How will this development affect the security of the data?" And most importantly, "Will the clients be comfortable with the direction this development will take the system?" We have to answer all four of those questions before we move forward with any development.

Teaching Consumers about HMIS

Ann Denton

Q. Okay. Thank you, Kat. I have another question for Julia, which is: What enabled you to teach other consumers about the HMIS technology?

Julia Tripp

I didn't exactly. I had attended many trainings with coworkers where I had to listen to their presentations on data quality and data integration, policy and technical solutions. That enabled me to talk about it with my peers. I was also running the consumer advisory committee, and that was where I would practice talking about it. There were many false starts and stops, and I struggled with this complex information. But I had the consumer advisory committee read part of HUD's HMIS implementation guide, something which people didn't expect that we would do or could do. We struggled with it. I broke it down section by section and we'd talk about it. We'd read. We'd talk about it with each other. We then were asked to give feedback on it, and ultimately we embedded our perspective in it. This was during the development of the implementation guide.

I also sought the support of the CSP staff to teach the more complex pieces so that the participants would get the correct information. We also held two of the first consumer user groups in the country and that was as a result of me attending some of the service user groups for administration and staff and thinking "This would be so great if consumers could come, could use the same space, the same laboratories, see the same software, see how it works." So I talked with the staff and that was allowed. So right now, we're training for the Bring America Home project and the performance in September. We have a HMIS training built into that.

Today I'm able to reserve the same presentation rooms used for training the administrative staff and use the same equipment to do the training. Some of the staff now have come down and volunteered on their own time to do training for the staff, so it's been really exciting. This was originally a pilot project. While I did lack the clout to make it happen statewide, I had

the freedom under my contract with QED (the HMIS contractor) and had to settle to have a national impact, specifically with HUD.

Obtaining Informed Consent

Ann Denton

Q. Another question for Julia from Reno, Nevada, from Restart, an organization I know and like. The questioner says, "I realize better than ever now the importance of consumer involvement in obtaining consent. Having said that, what do you recommend in terms of how to format the consent form? Should it not be part of an application packet and rather be given along with brochures that you have spoken of?"

Julia Tripp

I was not the person that spoke of brochures. Actually Kat did, but I would say that when I was going through the system, I was getting packets from different agencies and I really couldn't decipher all of them. It was like these chunks of information that I couldn't break down. I think the consent should be done separately and clearly. Or, if people are participating in some trainings, whether it's an intensive education or whether "This is what we're doing, this is why we're doing it," sort of a simple explanation, it should be included. But when you start talking about consent, you should do it clearly, you should repeat it, you should ensure that people can read it back to you or can tell you back what they thought they heard and understand what they are consenting to. Kat, would you like to address that, too?

Kathleen Freeman

Sure, Julia. My take on that is it's very important that your intake workers understand privacy and confidentiality, because we're using educational materials for that second step. The first step should always be that the intake worker explains what you're collecting data for, who it's going to go to, and what

it's being used for. They're the front line. That should be a one-on-one conversation between them and the client. When a client's interest is peaked, then we're hoping that they'll go to the educational materials and read them at their leisure. We're going to have a distribution center at each agency where they can just walk over and pick up the brochure or walk over and read a poster.

I agree with Julia. I think when you're coming in to a shelter or to an agency for services, you provide and you get so much information. So it's important that your intake workers understand privacy and confidentiality and that they can relay that to the clients and use educational materials as a secondary step. That said, I would strongly encourage you to put in your implementation your HMIS policy and require that agencies provide, within 30 days of a new hire, confidentiality and security training and that it occurs annually thereafter and that, when you monitor your participating agencies, that becomes part of the process.

Julia Tripp

Exactly. I would just add that you should ensure consumers are part of the policies and procedures committee, so they're there to help tweak that on this annual monitoring basis.

Linda Corey

I would also stress that it be presented in more than one way; not just handing it to a person, but actually checking to see that they understand it and know what they're signing.

Ending the “Us-and-Them” Divide

Caller

Q. Hi. I'm a formerly homeless person and I'm involved in consumer advocacy. There's something that I wanted to add to this, a point of view that I didn't think was being hit upon really strongly. That is that, in addition to the day-to-day problems and challenges, we're dealing with a major social issue: homelessness is something that doesn't have to go on forever. By involving consumers, we break down the sense of “us and them” from both sides. It's a way to strive towards more equity in society in general. Thank you.

Ann Denton

I think that's a great comment. Do any of the presenters want to respond?

Kathleen Freeman

I totally agree with that. We have a new director of homeless initiatives here in our State whose job is to coordinate system and policy changes needed to implement our action plan to end homelessness. We had a very interesting conversation about system security and hackers and people stealing identities and all of these different things. Her comment was “It's very interesting how we treat homeless people different than we do ourselves.” Because we tend to put homeless people in a little box and create these controls and constraints around them when we have the same concerns. It was just very interesting for her that it really was an “us and them” kind of thing. From my point of view, I try to implement security that protects your data more than protects my data, but I think that's a very valid point to have brought to this conversation.

Julia Tripp

I'd like to address that as well. One barrier to achieving equal partnership of consumers in HMIS implementation is that whole “us versus them.” I think this whole process for me was born of seeing

the separation, but yet being privy to these meetings and being privy to these trainings, seeing that there were people that were learning how to take care of us when we needed to learn how to do this for ourselves. Even if we could do no more than participate in the execution of a service, we needed to understand why these things are being done, what was being done for us and maybe, eventually, be able to take on that responsibility for ourselves.

One of the biggest barriers is the exclusivity of withholding or controlling knowledge and information as a privilege. Some perceive other homeless people as incapable or unworthy of participation and incapable of decisions and learning. Kat spoke of one group being a decision maker and another group being a service receiver. That's unfortunate, because no matter how much you think a person can or cannot understand, they have the right to struggle with new information, to be part of a decision-making community and to be accepted. Too often, certain subpopulations are discriminated against even within the advocacy community. This is something that bothered me and continued to drive me to write and talk about this.

I was, despite the fact that I was participating with the Center of Social Policy in work groups, often within other advocacy groups. I would notice discrimination, because I struggled with speech, because I didn't seem highly functional. I managed to make my way into the ranks, but I was made to feel like I didn't deserve to be there. This continued that "us versus them" atmosphere. My hope is that consumers and providers will sit down and talk and have the same knowledge. I love the term "equal partnership." This concept was basically designed to include the people that were most marginalized as well as higher-functioning people to be able to engage in dialogues.

Linda Corey

Julia mentioned the phrase, "Nothing about us without us." A few years back the disability communities took that on because we found that, as people with different disabilities and different social needs, we often had many needs that were similar. Coming together and fighting for a cause made the

whole process stronger when we were talking to legislators and other people who make changes. If we can work with professionals on an equal level, then we can come together over funding cuts and present a stronger force.

Paying for Consumer Involvement

Ann Denton

Q. Okay. This question must be from a bureaucrat: Who is paying for the printing and distribution of educational materials?

Kathleen Freeman

The Maine State Housing Authority, who is the lead agency for the HMIS project, has stepped up to the plate. We're going to pick up the costs of the printing and distribution. We hope the advocates will help educate the clients because we're hoping to help the advocacy group grow to a statewide organization. We're helping them pay for materials and things that they'll need.

Ann Denton

Thank you.

Julia Tripp

I'd like to address from the Center's point of view how we funded the work there. The Center for Social Policy at UMass Boston is a research institute, so they're very different from a State agency or direct service agency. Within the context of research funding, we were able to set aside so much for consumer participation. They would tell me how much is available, ask me how many people I planned to include over a span of time. Now we're building into our research projects a line item specifically for consumer feedback. I'm writing a white paper on consumer involvement in HMIS, which will be available soon on the Center for Social Policy's Web site. We're having consumers read it and give us feedback. For that, they're receiving a stipend. What we haven't figured out is exactly how to get correct constituency feedback in the different areas, but we

have figured out how to make the funding available for this.

Final Thoughts and Conclusion

Ann Denton

Q. Okay, great. This is the last e-mail question I have and it's for Julia: Are there any other lessons you would like to share?

Julia Tripp

Yes. As a society, we must learn to listen to the voice of the poor, the homeless, the mentally ill, and the disenfranchised. No matter how painful that voice may be to listen to, they know what they need; they will tell you if you ask and, most of the time, they know exactly what they're talking about even if, like me once, they can't say it very well. Lastly, successfully bringing the voice of homeless consumers into the HMIS implementation process is a great civil rights success. Thank you.

Ann Denton

Thank you. That may be a good note to end on. I want to remind everyone to visit the PATH Web site at www.pathprogram.samhsa.gov for other resources.

Finally, I want to thank all of our featured presenters: Julia, Kat, and Linda. Please watch for announcements of future teleconferences, which will be sent out on the PATH Listserv. With that, our call is concluded. Thank you all for participating. ■